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Offering the best death possible: Supporting people using substances at the end of life

Substance use services for people who are at, or near, the end of their lives are lacking. In an ageing population worldwide, where people are living longer with manifold social and health care needs (1), substance use is increasingly among the activities that people will die with, and of. Substance use services must be ready, willing and able to respond.

Keywords: *end of life, palliative care, alcohol, drugs, substance, partnership, assessment*

By 2060, it is forecast that 48 million people worldwide will need, but will die without, palliative care at their end of lives, an increase of 87% from 2016 (2). Practice-based reports suggest an increasing number of these people will be using substances and there will not be enough palliative services to cope. Unfortunately, empirical evidence to underpin practice development is scarce. Our Rapid Evidence Assessment (REA) (2004-2016) on this topic found no evidence of existing practice models to support people with co-existing substance use and palliative or end of life needs despite this being the primary focus of the search (3). Even with wider search parameters, only five of the 60 papers included in the REA were published in substance-focussed journals. These included papers from the UK and Sweden focussing on changing patterns of illness or causes of death among drug users (4) (5), definitions of UK drug-related mortality (6) and, as with the majority of papers in the REA, North American research focussing on “opioid abuse” in cancer patients (7) or “drug diversion” (8). Since the REA there has only been one further paper from Italy but it focussed on the incidence of “alcoholism” in two cohorts of patients with advanced cancer (9). There is, therefore, an indisputable gap in the evidence base to guide the practice responses of substance use professionals meaning it is the role of front-line substance use services to develop their own models for policy and practice.

Given the lack of international evidence on this topic, I highlight three key recommendations for practice from our multi-strand study exploring a range of perspectives on care for people using substances at the end of their lives (10). Based in the Midlands and North West of England, such recommendations may need international adaptation to suit different theoretical or practice models of substance use support. However, there are no surprises and their applicability to international settings is likely to need only limited adaptation.

The first recommendation is that substance use professionals need training and education to *identify* when someone is nearing the end of their life and *assess* their needs. Given that people attending substance use services will often have a plethora of co-existing physical and mental health needs, one of the challenges for professionals is to determine who is near the end of life and who is not. This can vary according to the medical condition, with cancer deaths being viewed as more predictable while organic deaths offer greater uncertainty. This is not an exact science but there are tools available to help people to have those conversations and to talk about people's needs and wishes at the end of their life (11, 12). It is not about diagnoses, it is about having a conversation with people and knowing where that starts.

There are clearly transferable skills for substance use practitioners between talking about problematic alcohol and other drug use to talking about advanced planning for death and dying – both considered difficult and sensitive subjects. Training exchanges between neighbouring substance use and palliative or end of life care teams is a cost effective and mutually beneficial way of providing knowledge and building collaborative relationships. Knowing what questions to ask, how, and when, will help to overcome concerns about raising the subject. Organisational 'champions' can also be appointed to oversee such work, lead on early collaborations, and to drive the development forward within each service.

The second recommendation is for substance use services to evidence their commitment by monitoring and recording the extent of palliative and end of life needs among people in their own services. There are very limited prevalence data on the number of people using substances at, or near, their end of life, apart from two small sample European studies exploring "alcoholism" among advanced small cohorts of cancer patients, (13) (14) and a later North American study on a large sample of veterans (15). This remains a considerable hole in data monitoring and recording. A regular self-audit of people attending the substance use service using a tool such as SPICT (16) or the Surprise Questionⁱ (17) can help begin to fill the data gap, if only at a local or organisational level.

Third, there is the old chestnut of partnership working. In our study (10), one area of concern arose repeatedly; professionals' experiences of poor and dismissive primary and acute care for people with current, or past, substance use. Their substance use histories were perceived as diverting adequate health responses away from their (serious) presenting medical needs. This was resolved in several examples by considerable time being taken to build relationships with local General Practitioners, attending appointments with the person by way of advocacy, and building a collaboration with a

local “end of life consultant”. However, partnership also includes working with family members, both as a source of information about their dying relative, and also to support family members in their own right. Such collaborative working not only instils greater knowledge and confidence, it also helps develop a mutual understanding about services, structures and the person themselves.

In sum, there exists only a small body of empirical work on this subject at present (3) leaving many gaps for future research. In the meantime, substance use professionals need to step over the evidence gap, continue to develop good practice, and ensure it is embedded in organisational policy. This is one area where coal-face leadership is vital. It is clear that specialist end of life services will be unable to cope with future demand. It is also clear that substance use services need to act quickly to support both the workforce and the people in their care.

Free *Good Practice Guidance* and *Policy Standards* for working with people using substances at the end of their lives are available to download at: <https://endoflifecaresubstanceuse.com/reports-and-resources-2/>

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ⁱ "Would you be surprised if the patient were to die in the next year?"